

**Report of Medicaid Services for  
Persons who are Medically Fragile, Technology Dependent  
Public Act 95-0622  
January 2022**

**Reporting Period: State Fiscal Year 2019 (July 1, 2018 – June 30, 2019) and  
State Fiscal Year 2020 (July 1, 2019 – June 30, 2020)**

**INTRODUCTION**

Effective September 17, 2007, [Public Act 95-0622](#) amended the Illinois Public Aid Code to require the Department of Healthcare and Family Services (HFS) to submit this bi-annual report to the Governor and the General Assembly outlining Medicaid services offered to children and young adults with disabilities who are medically fragile and technology dependent (MFTD).

Under section 5/5-2b of the Public Aid Code, the Department is required to ensure that medical assistance be available to children who qualify as persons with a disability, as defined under the federal Supplemental Security Income program, and who are medically fragile and technology dependent. The statute requires that eligible children be afforded medical assistance under Article V of the Public Aid Code in the community. The Department administers medical assistance to this population through a home and community-based Medicaid waiver authorized under section 1915(c) of the Social Security Act. Through the MFTD Waiver, and with the involvement of the University of Illinois' Division of Specialized Care for Children (DSCC), Illinois provides care coordination, regular Medicaid State Plan services, and additional waiver-only services to the MFTD population as required under the Public Aid Code. The MFTD waiver was last renewed effective September 1, 2017, and the most current amendment is was approved by the Centers for Medicare and Medicaid (CMS) on February 10, 2020. A new amendment has been submitted and is currently under review. The effective date, pending CMS approval, is January 1, 2022.

In compliance with Public Act 095-0622, this report includes the following information concerning the MFTD waiver program:

1. The number of customers who currently receive waiver services;
2. The nature, scope, and cost of services;
3. The comparative cost of providing those services in a hospital, skilled nursing facility, or intermediate care facility;
4. The funding source for the provision of services, including federal financial participation;
5. The qualifications, skills, and availability of caregivers for children receiving services; and
6. The number of children who have aged out of the services offered under paragraph 7 of the section 5-2 during the two years preceding the report.

**1. Number of Persons Who Currently Receive Waiver Services**

The number of customers served in the MFTD Waiver fluctuates regularly. At the beginning of State Fiscal Year 2019, which began on July 1, 2018, there were 1,264 customers eligible to receive services through the MFTD Waiver. At the beginning of State Fiscal Year 2020, which began on July 1, 2019, there

were 1,310 customers eligible to receive services through the MFTD Waiver. There were 1,185 unique customers who received waiver services during both State Fiscal Years 2019 and 2020.

**2. The nature, scope, and cost of services**

MFTD Waiver customers receive regular State Plan Medicaid services, as well as special services available only to waiver customers.

Of all services utilized, MFTD waiver customers most frequently used nursing services, inpatient hospital care, prescription drugs, and durable medical equipment and supplies, all of which are services provided under the Medicaid State Plan. Medicaid State Plan service expenditures for MFTD Waiver customers in State Fiscal Year 2019 are shown in Figure 1-a below and expenditures for State Fiscal Year 2020 are shown in Figure 1-b.

**Figure 1-a**

| <b>Regular Medicaid State Plan Services Provided to MFTD Waiver Customers<br/>State Fiscal Year 2019<br/>Total Waiver Customers: 1,264</b> |   |                                   |  |
|--|---|-----------------------------------|--|
| <b>Basic Medicaid Service</b>  | <b>Unduplicated Customers Receiving Service</b> | <b>Total Service Expenditures</b> | <b>Average Service Expenditures Per Customer</b> |
| Nursing Services   | 1,090   | \$82,853,432                      | \$76,012   |
| Inpatient Hospital Care  | 541   | \$48,810,607                      | \$90,223   |
| Prescription Drugs   | 1,102   | \$15,388,608                      | \$13,964   |
| Medical Supplies   | 1,124   | \$9,231,241                       | \$8,213  |
| Medical Equipment  | 998   | \$5,131,209                       | \$5,141  |

**Figure 1-b**

| <b>Regular Medicaid State Plan Services Provided to MFTD Waiver Customers<br/>State Fiscal Year 2020<br/>Total Waiver Customers: 1,310</b> |   |                                   |  |
|--|---|-----------------------------------|--|
| <b>Basic Medicaid Service</b>  | <b>Unduplicated Customers Receiving Service</b> | <b>Total Service Expenditures</b> | <b>Average Service Expenditures Per Customer</b> |
| Nursing Services   | 1,030   | \$65,743,338                      | \$63,828   |
| Inpatient Hospital Care  | 519   | \$46,941,030                      | \$90,445   |
| Prescription Drugs   | 1,130   | \$15,123,138                      | \$13,383   |
| Medical Supplies   | 1,163   | \$10,262,587                      | \$8,824  |
| Medical Equipment  | 1,048   | \$6,043,901                       | \$5,767  |

Expenditures for waiver-only services are significantly lower than costs for the regular State Plan Medicaid services. Fiscal Year 2019 expenditures for waiver-only service for MFTD Waiver customers are shown in Figure 2-a below and expenditures for State Fiscal Year 2020 are shown in Figure 2-b. A decrease in utilization and expenditures for waiver only services is noted in State Fiscal Year 2020. This can be attributed to the COVID-19 pandemic as many families refused to allow workers into their homes to limit exposure risks.

**Figure 2-a**

| <b>MFTD Waiver Services only<br/>State Fiscal Year 2019<br/>Total Waiver Customers: 1,264</b> |   |                                   |  |
|---|---|-----------------------------------|--|
| <b>Waiver Service</b>   | <b>Unduplicated Customers Receiving Service</b> | <b>Total Service Expenditures</b> | <b>Average Service Expenditures Per Customer</b> |
| Respite/Nursing hours   | 539   | \$12,255,872                      | \$22,738   |
| Environmental Modification  | 343   | \$743,417                         | \$2,167  |
| Special Equipment   | 0   | 0                                 | 0  |
| Nurse Training  | 235   | \$66,819                          | \$284  |
| Placement Counseling  | 0   | 0                                 | 0  |
| Family Training   | 0   | 0                                 | 0  |

**Figure 2-b**

| <b>MFTD Waiver Services only<br/>State Fiscal Year 2020<br/>Total Waiver Customers: 1,310</b> |   |                                   |  |
|---|---|-----------------------------------|--|
| <b>Waiver Service</b>   | <b>Unduplicated Customers Receiving Service</b> | <b>Total Service Expenditures</b> | <b>Average Service Expenditures Per Customer</b> |
| Respite/Nursing hours   | 411   | \$7,687,636                       | \$18,705   |
| Environmental Modification  | 68  | \$163,414                         | \$2,403  |
| Special Equipment   | 0   | 0                                 | 0  |
| Nurse Training  | 153   | \$32,643                          | \$213  |
| Placement Counseling  | 0   | 0                                 | 0  |
| Family Training   | 0   | 0                                 | 0  |

Figure 3-a below details the five largest categories of regular State Plan Medicaid services, and all other expenditures, by cost and percent of total costs in State Fiscal Year 2019, for children enrolled in the MFTD waiver. Figure 3-b details expenditures for State Fiscal Year 2020.

Utilization of most State Plan Medicaid Services remained stable from year to year with minimal fluctuation. However, Home Health Services had a sharp increase from \$72,693 in State Fiscal Year 2019, to \$16,190,517.85 in State Fiscal Year 2020. This increase is not due to an actual increase in utilization, but rather a result of improved reporting of Managed Care encounters.

Figure 3-a

| <b>MFTD Basic Medicaid Services Detailed Expenditures</b><br><b>State Fiscal Year 2019</b><br><b>Total Customer: 1,264</b>   |                      |                |
|--|----------------------|----------------|
| <b>Service Breakdown</b>   | <b>Total Cost</b>    | <b>Percent</b> |
| Nursing  | \$82,853,432         | 44.7%          |
| Inpatient Hospital   | \$48,810,607         | 28.1%          |
| Prescription Drugs   | \$15,388,608         | 8.86%          |
| Medical Supplies   | \$9,231,241          | 5.31%          |
| Medical Equipment  | \$5,131,209          | 2.95%          |
| All Other Services Total ( <i>Breakdown below</i> )  | \$12,268,851         | 7.06%          |
| <b>Total Expenditures</b>  | <b>\$173,683,947</b> | <b>100%</b>    |
| <b>Breakdown of All Other Services</b>   |                      |                |
|  | <b>Total Cost</b>    | <b>Percent</b> |
| Physician Services   | \$3,683,036          | 2.12%          |
| Outpatient Services  | \$2,776,009          | 1.6%           |
| Therapies (physical, occupation, speech)   | \$749,466            | 0.43%          |
| Early Intervention Services  | \$450,967            | 0.26%          |
| Home Health Services   | \$72,693             | 0.04%          |
| All other Medical Services (lab, x-ray, optical, dental, audiology, podiatry, healthy kids services, mental health, transportation, and others including school based) | \$4,536,680          | 2.61%          |

Figure 3-b

| <b>MFTD Basic Medicaid Services Detailed Expenditures</b><br><b>State Fiscal Year 2020</b><br><b>Total Customers: 1,310</b>  |                      |                |
|--|----------------------|----------------|
| <b>Service Breakdown</b>   | <b>Total Cost</b>    | <b>Percent</b> |
| Nursing  | \$65,743,338         | 38.46%         |
| Inpatient Hospital   | \$46,941,030         | 27.46%         |
| Prescription Drugs   | \$15,123,138         | 8.85%          |
| Medical Supplies   | \$10,262,587         | 6%             |
| Medical Equipment  | \$6,043,901          | 3.54%          |
| All Other Services Total ( <i>Breakdown below</i> )  | \$26,805,500         | 15.67%         |
| <b>Total Expenditures</b>  | <b>\$170,919,493</b> | <b>100%</b>    |
| <b>Breakdown of All Other Services</b>   |                      |                |
|  | <b>Total Cost</b>    | <b>Percent</b> |
| Physician Services   | \$3,369,152          | 1.97%          |
| Outpatient Services  | \$2,620,084          | 1.53%          |
| Therapies (physical, occupation, speech)   | \$588,014            | 0.34%          |
| Early Intervention Services  | \$357,665            | 0.21%          |
| Home Health Services   | \$16,190,518         | 9.47%          |
| All other Medical Services (lab, x-ray, optical, dental, audiology, podiatry, healthy kids services, mental health, transportation, and others including school based) | \$3,680,067          | 2.15%          |

**3. Comparative Cost of Providing Services in a Hospital, Skilled Nursing Facility, or Intermediate Care Facility**

Figures 4-a and 4-b compare the service costs for MFTD Waiver customers to average annual costs, including ancillary costs, of providing services to a similar population in an institution such as a hospital or nursing facility. State fiscal year 2020 resulted in a slight decrease in total waiver expenditures which can be attributed to the COVID-19 pandemic and many families refusing to allow workers into their homes to limit exposure risks.

**Figure 4-a**

| <b>Comparison of Costs Per Customer for Services Provided in the MFTD Waiver and Services Provided in an Institution State Fiscal Year 2019</b> |  |                                       |  |   |
|---|--|---------------------------------------|--|---|
| <b>Level of Care</b>  | <b>Number of MFTD Waiver Customers</b> | <b>Total MFTD Waiver Expenditures</b> | <b>Average Expenditure per Waiver Customer</b> | <b>Average Expenditure per Institutional Customer</b> |
| Hospital/Nursing Facility   | 1,264                                  | \$173,683,947                         | \$137,408                                      | \$249,319   |

**Figure 4-b**

| <b>Comparison of Costs Per Customer for Services Provided in the MFTD Waiver and Services Provided in an Institution State Fiscal Year 2020</b> |  |                                       |  |   |
|---|--|---------------------------------------|--|---|
| <b>Level of Care</b>  | <b>Number of MFTD Waiver Customers</b> | <b>Total MFTD Waiver Expenditures</b> | <b>Average Expenditure per Waiver Customer</b> | <b>Average Expenditure per Institutional Customer</b> |
| Hospital/Nursing Facility   | 1,310                                  | \$170,919,493                         | \$130,472                                      | \$265,091   |

**4. Funding Sources for the Provision of Services, Including Federal Financial Participation**

Funding for MFTD waiver services is appropriated to HFS from the General Revenue Fund. Through an interagency agreement, the DSCC has authority to pay home health nursing agency providers for nursing and waiver services out of the HFS appropriation. Other medical services for children enrolled in the waiver are paid directly by HFS from its appropriations for hospital, physician, home health, and other services.

Illinois submits its claim expenditures to the federal government, which reimburses the state for a portion of those costs. During this reporting period of State Fiscal Years 2019 and 2020, the state received reimbursement from the federal government at a rate of 51.31%.

**5. Qualifications, Skills, and Availability of Caregivers for Children Receiving Services**

Home Health Agencies

Although Illinois has 406 Medicaid home health agencies, only a specialized group of 72 nursing agencies serve the technology-dependent pediatric population with in-home shift nursing care. There are also four alternative childcare models enrolled with HFS and approved by DSCC to provide respite and

transitional care services in the waiver program. These are licensed as community-based health care centers.

DSCC has specific guidelines for approving providers of private duty nursing services under the waiver. Once approved, and annually thereafter, agencies sign an agreement with DSCC to comply with the program requirements, including qualifications, experience, and training for administrative and nursing staff.

Appropriately qualified staff comprised of registered nurses (RNs), licensed practical nurses (LPNs) and certified nurse aides (CNAs), all of whom are licensed or certified in Illinois, provide respite care services for children in the MFTD Waiver. The same qualifications apply to State Plan private duty nursing services. Nurses and CNAs must be employed by a DSCC-approved nursing agency unless they provide services in a children's community-based health center and are employed directly by the health center. DSCC has difficulty finding nurses or nursing agencies to serve some areas of the State. However, through various outreach activities, five new nursing agencies have enrolled with DSCC in the past two years and have begun providing shift-nursing services to this population.

#### Environmental Modifications and Specialized Medical Equipment and Supplies

Providers of environmental modifications and specialized medical equipment and supplies, like all Medicaid waiver providers, are subject to applicable requirements regarding licensure, qualifications, and experience. In addition to HFS enrollment requirements, DSCC approves MFTD Waiver home medical equipment and infusion providers and requires annual signed agreements. There are 948 home medical equipment providers enrolled in the Medicaid Medical Assistance Program. Of that number, 22 meet the additional DSCC requirements for services to waiver children. Six new home medical equipment providers have enrolled with DSCC and begun providing services to this population.

#### Placement Maintenance Counseling

Placement maintenance counseling provides short-term, issue-specific family counseling or individual counseling for the purpose of maintaining the child in the home. Placement maintenance counseling is provided by a licensed social worker, licensed clinical psychologist, or an agency certified by Department of Human Services (DHS), Division of Mental Health (DMH), or Department of Children and Family Services (DCFS) to provide clinical or rehabilitation services. To receive payment for these services, medical providers must be enrolled with HFS.

### **6. Number of Children who Aged Out of Services Offered Under the Waiver During the Two Years Preceding This Report**

With Federal CMS approval of the May 1, 2017 waiver amendment, individuals no longer age out of the waiver at age 21. Customers now have the option to remain in the MFTD waiver past their 21st birthday and continue to receive waiver services for as long as they so choose. In June 2020, there were 119 customers aged 21 receiving services through the MFTD waiver. In July 2021, this number grew to 151. The State expects the number of 21 and over customers to continue to grow.